



Treatment for cancer pain at the end of life: a case study in a palliative care service in the Autonomous City of Buenos Aires

El tratamiento del dolor por cáncer en el final de la vida: estudio de caso en un servicio de cuidados paliativos de la Ciudad Autónoma de Buenos Aires

Alonso, Juan Pedro¹

¹PhD in Social Sciences. Post-doctoral fellowship, Consejo Nacional de Investigaciones Científicas y Técnicas, Instituto de Investigaciones Gino Germani, Universidad de Buenos Aires, Argentina. juanpedroalonso79@gmail.com

ABSTRACT Cancer pain relief has been defined as a worldwide public health challenge in the last decades and has recently been included in public debates as a human rights issue. However, barriers to the provision of adequate pain management continue to exist. This article analyzes the cancer pain treatment provided in a palliative care setting in the Autonomous City of Buenos Aires, focusing on how professionals and patients implement and negotiate the terms and adherence to the pain treatment. Based on a qualitative approach that triangulates data from semi-structured interviews and from ethnographic observations, the article addresses the way pain is measured and assessed and the strategies of health professionals in establishing pain treatment protocols. The article also describes the rhetoric regarding the right to pain relief developed by health professionals through their practice and discusses the limitations of that rhetoric.

KEY WORDS Pain; Neoplasms; Hospice Care; Patient Rights; Argentina.

RESUMEN La prevención y el alivio del dolor por cáncer, definidos en las últimas décadas como un desafío para la salud pública a nivel internacional, han sido planteados recientemente en los debates públicos como una cuestión de derechos humanos. Pese a ello, existen importantes barreras para la provisión de tratamientos adecuados. El artículo analiza el tratamiento del dolor por cáncer en un servicio de cuidados paliativos de la Ciudad Autónoma de Buenos Aires, poniendo el foco en la forma en que profesionales y pacientes instrumentan y negocian los términos y la adherencia al tratamiento del dolor. A partir de un abordaje cualitativo, que triangula datos de entrevistas semiestructuradas y observaciones etnográficas, el artículo describe la forma en que el dolor es objetivado y medido, y las estrategias de los profesionales para consensuar los protocolos de tratamiento. Asimismo, se describe el modo en que los profesionales construyen en la práctica una retórica del derecho al alivio del dolor y se discuten sus límites.

PALABRAS CLAVES Dolor; Neoplasias; Cuidados Paliativos al Final de la Vida; Derechos del Paciente; Argentina.

INTRODUCTION

"Fighting against pain" is a relatively new imperative in western medicine: only at the end of the twentieth century was the fight against pain defined as a public health priority (1). In the 1980s, the World Health Organization (WHO) promoted cancer pain prevention and relief as one of the greatest challenges in public health and urged health care services to ensure cancer patients' right to relief from avoidable pain (2). More recently, and thanks to the development of palliative care, pain relief began to be shaped as a human rights issue (3,4). As stated by Brennan *et al.*, in the last years, developments in the fields of medicine, ethics and law have given rise to an international consensus that considers failure to treat pain as "poor medicine, unethical practice, and [...] the abrogation of a fundamental human right" (5 p.206).

Despite these developments and breakthroughs – and the methodological difficulties in estimating pain prevalence – previous research and literature reviews show that most cancer patients do not have access to pain relief treatments, an issue that continues to be a public health concern at an international level (3-7). Among the causes of this imbalance are issues related to public health policies which fail to ensure the availability, accessibility and affordability of opioids; the inadequate training of health professionals; and the representations shared by patients and professionals which hinder access to an effective treatment, such as the inevitability of pain and fear of addiction and opioid dependence, among others (5,6). In Argentina, there are no epidemiological studies of cancer pain prevalence; however, based on indicators such as the average consumption of opioids, used by the WHO as criterion to measure progress in cancer pain treatment, it is estimated that a large percentage of Argentine oncology patients do not have access to appropriate treatments (8) (a).

The aim of this article is to analyze cancer pain treatment at the end of life, focusing on how palliative care professionals and patients implement and negotiate the terms of and adherence to pain management in practice. This work is framed within a broader research study regarding how the

end of life is managed in palliative care units, a medical discipline specialized in the care of terminal patients. Defined as an approach aimed at improving the quality of life of patients and relatives through the prevention and alleviation of suffering using a multidisciplinary approach (9), palliative care bases its expertise on the assessment and treatment of distressing symptoms, especially the management of cancer pain (10).

Based on a case study and using a qualitative methodological approach, this article analyzes the strategies of palliative care professionals to come to agreement with patients on the terms of pain management in clinical appointments. This requires pedagogical work regarding the implementation of scales and the benefits of preventive treatment, getting patients committed to the treatment, and working through the negative views which many patients have regarding opioids, all as part of a rhetoric that considers pain relief as a right.

Cancer pain management

The first studies addressing the topic from a social sciences perspective explored the influence of culture and socialization on the manifestations of and attitudes related to pain (11). In the last decades, the sociology of health and medical anthropology have extensively explored the issue of chronic pain. Research studies explore how chronic pain is managed in certain medical facilities such as clinics where these types of pathologies are treated (1,12-15), as well as the subjective experience of living with chronic pain and how this experience affects the body and subjectivity (16-19). On the other hand, the creation of pain management as a medical specialty (1), as well as the concepts and breakthroughs in the therapeutics of cancer pain in the palliative care field (10,20,21) have been analyzed from a socio-historical perspective.

Several authors have criticized the biomedical conception of pain, defined as a feeling which may be measured objectively, classified and treated through universal parameters (16,22,23). However, in the last years, the prevailing paradigm in the conceptualization of pain within the medical world has been modified, highlighting the

centrality of social, cultural and psychological elements (1,20,21).

Starting in the second half of the twentieth century, pain management underwent important conceptual and technical innovations (20). The first was the emergence of a medicine focused on pain, brought about by John J. Bonica, an American anesthesiologist. This new medicine, which defines pain as its object – and not as a mere symptom – is based on a holistic focus on the person and proposes a multidisciplinary approach for research on and treatment of pain (1). In addition, the work of Cicely Saunders – a central figure in the emergence of palliative care – contributed to the creation of a medicine focused on pain whose conceptualization integrates psychological, social, emotional and spiritual aspects of pain and studies the use of opioids for pain control at the end of life (21). Furthermore, in the last decades, new ways to measure and assess patients' pain and the analgesic effects of therapies were developed (24) and pain management protocols for oncologic diseases were created (25).

These developments are embraced in the WHO regulations regarding cancer pain management and are defined by the following elements:

- a. the control of this type of pain requires a preventive treatment (analgesics are prescribed at regular intervals and not based on the patient's momentary need);
- b. the evaluation of pain intensity and treatment efficacy is carried out using numerical scales;
- c. analgesics are adapted to pain intensity, so that the power of the drug is adjusted according to the intensity of the pain (9,25).

This article analyzes the practical implementation of this protocol; that is to say, how palliative care professionals and patients negotiate and define the meaning, the adherence to, and success and failure of the treatment in the daily interactions at the hospital by adopting a rhetoric based on the right to pain relief.

METHODOLOGY

The data analyzed in this article is part of a research study carried out with professionals and patients of a palliative care unit at a public hospital in the Autonomous City of Buenos Aires between the years 2006 and 2009 (b). The methodological design followed a qualitative strategy (26), based on a combination of data collection techniques such as ethnographic observation conducted in the unit and semi-structured interviews and informal talks with professionals and patients.

The ethnographic fieldwork (27) consisted of participation in different spaces and situations in this unit, such as team meetings, medical rounds and medical appointments with patients and relatives over a period of thirteen months. Semi-structured interviews with professionals and patients were carried out (c). Twenty-four members of the palliative care unit were interviewed (seven doctors, two psychologists, nine nurses, one social worker, one occupational therapist and four lay volunteers). An intentional sample of patients (controlled by gender and the age of participants) was constituted: thirty patients were interviewed, sixteen women and fourteen men, with an average age of 58 years. Patients were contacted in the unit, where a meeting to carry out the interviews was agreed upon. The interviews took place at the hospital's café, in the patients' private rooms or in the unit's conference room, while others were carried out in the patients' homes. In each case, the interviews were carried out in a space where the interviewees' privacy was respected and palliative care unit professionals were not present.

The interviews and observations were carried out with the consent of patients and professionals, who were informed of the nature and objectives of the research. This study was authorized by the authorities of the unit and approved by the Education and Research Ethics Committees of the hospital. Details in the quoted material of the interviews and observations have been omitted or modified in order to preserve the participants' anonymity. The ethnographic fieldnotes, along with the transcribed text of the interviews, were coded in a program for the analysis of qualitative data (ATLAS.ti) using inductive analysis (28).

The decision to carry out research in only one unit was made in order to prioritize a longer involvement in the same place, a choice that also brings with it logical limitations regarding the possibility of extrapolating the results. In the choice of the unit – a pioneer in the discipline and a role model in Argentina and Latin America (d) – issues related to feasibility (which are important in these types of projects) as well as to case relevance were considered (29).

RESULTS

Pain management in palliative care

Pain control is one the main motives for patient consultations to the palliative care unit. Except for those cases in which patients are explicitly referred for more effective pain management, most patients describe past experiences of neglect or lack of recognition of their pain in health facilities (30). In analyzing these trajectories, the difficulty faced by patients to find answers for their pain experiences is evident:

Interviewer: *You didn't receive pain treatment before?*

Patient: *No, the other doctor didn't give me anything. He told me that he couldn't give me anything else because it was too strong. So he didn't give me anything.*

Interviewer: *Did you ever ask for pain medication?*

Patient: *Of course I did, I asked for something for the pain, but he only prescribed me ibuprofen, which worked the first few days, but then stopped working. Because the pain was so strong that it had no effect at all.* (Interview with a female patient, aged 62)

In the patients' descriptions (both in the interviews as well as in remarks made during first consultations at the pain relief unit), the lack of knowledge and caution regarding the use of opioids on the part of some professionals can be observed, as well as the difficulty these professionals have in listening and responding to patients' requests.

For palliative care professionals, "acknowledging as true the experience of pain expressed

by the patient" (as one interviewed doctor highlighted) is the starting point of the treatment. Unlike in patients' previous experiences, palliative care professionals encourage the patients' participation in identifying and reporting feelings of pain. As one interviewed patient stated:

I feel bad because my pain is nothing compared to what you can see other patients feel, there are patients that are really bad. You can see them really dragged down by the pain. But I can't stand this pain anymore, I don't want to suffer anymore, my body can't tolerate any more pain. [The doctor] taught me that my pain was mine, and that something had to be done about it. (Interview with a female patient, aged 54)

This "pedagogical" work – focusing on the health professionals' definition of pain relief as a right – is constant in the medical consultations. We will next analyze how the terms of the pain management protocol are negotiated and agreed upon in practice to later discuss the formulation of a rhetoric of pain relief and its limits.

Objectifying the subjective experience of pain

In order to accomplish the analgesic aims of the treatment it is necessary to assess pain intensity before and during the treatment. One of the predictors of inadequate pain management is the discrepancy between patient and doctor in the estimation of pain intensity, as well as the problems in measuring intensity (32). At the pain treatment unit, pain is assessed using a numerical scale, a widely used method to measure pain intensity in clinical contexts and identified as one of the most reliable (24).

Before or during the consultation, patients are asked to express how intense the pain they feel is. To do so, they are asked to state the number that best represents the intensity of their pain on a scale from 0 (absence of pain) to 10 (maximum pain conceivable). The number provided by the patient is recorded in his or her medical record along with other evaluated symptoms, such as fatigue, nausea, drowsiness, and so on. As a volunteer at the unit explained in an interview:

Volunteer: *The control of symptoms has a scale from 0 to 10. With first time patients, I write down their information and explain to them that I'm going to ask them some questions every time they have an appointment in order to keep track of the symptoms and evaluate their progress. Then, I ask them to rate their pain on an imaginary scale from 0 to 10 as I name each symptom, considering the last 24 hours. And they do it just fine.*

Interviewer: *Pain is assessed using these scales...*

Volunteer: *Pain, fatigue, nausea, lack of appetite, drowsiness, shortness of breath...* (Interview with a volunteer from the unit)

The use of this scale is novel to most patients, and it requires pedagogical activities on the part of professionals. Patients take some time to get used to this exercise of objectifying their pain. They later acknowledge the advantages of the exercise, as it allows them to objectify their subjective experience and easily communicate it to professionals, challenging the personal and non-transferable aspect which characterizes the experience of pain (27). As one patient commented in an interview:

Interviewer: *Had you ever used the scale to rate your pain before?*

Patient: *No, I never had. At first, it was a little hard to understand how it worked; but I thought it was great, because you can communicate to the professional what's going on, how much it hurts. I think it's a subjective objectification, because, we could say that somehow they try to make the communication of pain possible. I also think it's interesting because it's not that they rule out other ways of expressing what a person with pain experiences, in fact there is dialogue, and in this dialogue, the professional can start to realize if someone is getting better.* (Interview with a male patient, aged 37)

The scale allows patients to communicate their feelings to the professionals, who also use other types of information in addition to the scale to define treatments and evaluate their efficacy. In most cases, the information provided by the scale is not enough; therefore, the professionals must

rely on impressions and information that arise from interviews with the patient, such as his or her general well-being.

However, in some cases, there is greater difficulty in translating pain into numerical terms. Asked to rate their pain, some patients answer using qualitative descriptions (*"it doesn't hurt too much," "it hurts a bit less than the last time," "it hurts a lot," "I've been feeling better"*), or they assign a number at the insistence of professionals (*"So, would your pain be a four?"*) who remind patients of the importance on the measurement to evaluate the efficiency of the treatment.

A starting point for professionals is to acknowledge the feeling of pain expressed by the patient as real. Nevertheless, as an interviewed doctor declared: *"that does not mean that the treatment is always pharmacological,"* making reference to the "emotional" origin of some types of pain. As a doctor stated after working with an inpatient:

...it's amazing how patients many times express their suffering through pain. Therefore, they ask for an extra dose of drugs when what they really need is something else. In this case, she asked for medication, but she needed emotional support. (Interview with a doctor from the unit)

In these cases, there is discrepancy between the intensity reported by the patient and that assessed by the professionals, who consider it important to identify these cases in order to adjust the treatment by applying other therapeutic actions in addition to opioids. An interviewed doctor explains it this way:

It's good to diagnose the emotional dimension [of pain] in order to know what to expect in the management of the pain and in the effectiveness of the drugs. It is also good to talk it over with the patient and to try other things, for example an anxiolytic. That is to say, a patient rates his pain as 9, and as you get to know him, you could say that part of that 9 includes not only the strictly physical aspect but is aggravated by an emotional aspect. So, to manage that pain, you have to try using other things, for instance, an

antidepressant. (Interview with a doctor from the unit)

In all cases, the assessment of the treatment success or failure will be measured in terms of keeping pain at tolerable levels according to the patient, and not in binary terms (presence or absence of pain). Thus, the scale is a central element which allows for the observation of the patients' evolution over time and for the adjustment of treatment.

Negotiating the patient's views about opioids and preventive treatment

The WHO protocol for cancer pain management recommends increasing the analgesic power of drugs in accordance with the increase in pain intensity, a strategy called "analgesic ladder" (9). Firstly, it is advisable to prescribe non-opioid painkillers (such as paracetamol and ibuprofen); secondly, weak opioids (like codeine and tramadol); and thirdly, strong opioids (such as methadone, morphine and oxycodone).

The patients' views about opioid drugs constitute an important element in adopting and adhering to treatment. Negative views of opioids – especially morphine, due to its associations with terminal illness and the fear of developing dependence – are one of the main obstacles to treatment. In the words of one interviewed patient:

I was taking diclofenac. I didn't want morphine, you know? Morphine, uh! I thought I had already become a terminal patient. It's how you think about it. Then, the doctor told me: "I am going to suspend diclofenac, because it's going to damage your kidneys, your liver. Morphine isn't so damaging. That is, it has the same function, and the dose is so low that you won't develop dependence in the future." (Interview with a male patient, aged 63)

As can be seen here, professionals try to detect these fears and deconstruct negative views. Generally, in the first consultation, or when this type of medication is prescribed for the first time, professionals work with these preconceptions. In

these cases, the professionals' task is to contrast this view and question the association between morphine and terminal illness (*"in the movies morphine is given to people who are dying,"* remarks an interviewed doctor), informing the patient about the advantages of the medication in managing their pain. The following is an example of a first consultation:

The doctor asks the patient the primary reason for the consult, and the patient says that she has pain in her stomach, legs, genital area and rear. The doctor asks about previous treatments and the woman answers that she was treated with ibuprofen. Then the doctor asks: *"What do you know about morphine? What do you think about it?"* The woman retracts and says; *"Uh, doctor, morphine."* The doctor asks again: *"I want you to tell me what you know about morphine."* The woman answers: *"It is the last medication you prescribe to a patient."* Then the professional explains that morphine and morphine-derived painkillers are strong analgesics prescribed for strong pain such as hers. And he gives an example: *"If I fall off a balcony and break my leg into pieces, I'm going to be in a lot of pain and they'll have to give me morphine. Now, let's assume that I am dying and I am not in pain, nobody is going to give me morphine."* (Field notes, observation in consultation appointments)

These views do not apply exclusively to patients. In their narrations of previous care experiences, patients describe situations in which health professionals underestimated or inadequately treated their pain.

Other negative views of patients about morphine are related to dependence and the patients' fear of consuming high doses which would later prevent pain control. These views are influenced by the experiences of relatives or close acquaintances who died from cancer with situations of uncontrolled pain. For example, a patient's son states that his father does not adhere to the treatment because *"he's worried about what he's going to take when the pain gets worse; he's afraid because he saw his mother dying in a lot of pain."* For some patients, the delay in starting medication or the

initial low doses are a reassurance that they can adjust the treatment when the pain increases.

In connection with this point, other aspects that interfere with treatment are associated with the contrasting views between preventive pain management and the way pain is managed in daily life. According to the protocol, the management of this type of persistent pain requires a preventive treatment; therefore, analgesics are prescribed at regular intervals and not according to the patient's need at a given moment (9). The guidelines of preventive treatment are counterintuitive to some patients, who take the drugs according to their daily needs; that is to say, they take their medication just when they feel pain without following the schedule established by the professionals, and they stop taking it when the pain disappears. As an interviewed patient comments:

I used to take it only when I felt pain, and would suffer terrible pain until the drug took effect; sometimes the pain was so strong that I had terrible attacks. So I started taking the drug regularly, because they explained to me that if I reduced the dose, I would be in pain, and it would take a while until the dose took effect again and during that time I would be in some pain for a while. So, I was able to stop having pain. (Interview with a female patient, aged 47)

The professionals focus less on the explanation of this aspect of the treatments than on views about opioids, and the adjustments are usually performed when these problems arise in the consultations.

Another aspect to be taken into account in order to assess adherence to the treatments are the side effects experienced by some patients, such as constipation and drowsiness, which must be taken into account by professionals. An interviewed patient states the following:

Patient: I never accepted morphine; in fact, I always rejected it. But unfortunately I have to thank the morphine because the pain has almost completely stopped.

Interviewer: Has morphine caused you any problems?

Patient: Well, constipation, drowsiness, lack

of appetite. Some aggressiveness, because I rejected the medication. But the doctor made me understand that it is a medication that doesn't have a lot of consequences. (Interview with a male patient, aged 56)

While adherence can sometimes be difficult, when pain is really strong patients give less priority to these problems, as explained in the following citation:

At the consultation, a patient said: "I felt much better when I took morphine. The pain is unbearable, I can't sleep. It drives me crazy." The doctor requested the patient to tell her how he would rate his pain. He answered: "9". And the doctor told him: "But morphine made you too drowsy, that's why we changed to methadone." The patient answered: "I don't care. I'd rather be sleepy but pain-free." (Field notes, observation of consultation appointments)

Pain relief as a human right

Scarry's (31) work constitutes a starting point for considering pain treatment as a human right. In her analysis, this author argues that the attempts to objectify and create a language for pain (a *priori* defined as something subjective and indescribable, and which resists such objectification) is a project with practical and ethical consequences: "the relative ease or difficulty with which any given phenomenon can be *verbally represented* also influences the ease or difficulty with which that phenomenon comes to be *politically represented*" (31 p.12) [*Italics in original*]. Using a patient-centered approach, pain treatment in palliative care is included within this framework.

Different initiatives and strategies in several fields (medicine, bioethics, law, among others) have been identified worldwide to guarantee pain relief by shaping the issue as a matter of human rights (5). These strategies are based on national and international laws, such as the declaration of the right to health as an international human right (33), and ultimately aim to reduce the distance between the acknowledgement of this right and its practical application. In this paper, we are not

interested in addressing the formulation of pain relief as a right in an abstract sense, but in considering how this rhetoric is created and implemented by care professionals in their daily activities; that is, how professionals apply these notions and the way in which patients do or do not adopt them.

Firstly, it should be mentioned that once patients are referred to the palliative care unit, they do not usually understand pain relief as a right, partly due to the barriers mentioned: certain ideas about pain (as something unavoidable and associated to disease) or about opioids (fear of dependence, considering them as the last medical resource, and so on). This situation can be clearly observed through the patients' narratives reconstructing their experiences with pain, which are marked by a significant change upon their arrival at the palliative care unit. One patient highlighted in one of the extracts cited above: "[The palliative care doctor] taught me that my pain was mine, and that something had to be done about it." Similar expressions refer to the pedagogical work of the health professionals, aiming to help patients modify their ideas about pain and its treatment. Those interventions are intended to assist patients in identifying pain without minimizing or naturalizing it and in committing themselves to the treatment. As one doctor asked a patient in an observed consultation, "why do you have to bear the pain if there is something that can calm it?" Or as one doctor explained in the first consultation with a patient: "We don't want you to feel pain. At the slightest pain, you let us know immediately." Through carefully listening to the patients, encouraging them to commit to the treatment and teaching them not to underestimate, but to identify, describe, objectify and explain their pain, professionals create and reaffirm in their practice a rhetoric of the right to pain relief, framed within the initiatives to consider cancer pain relief as a human right.

This rhetoric has an effect on some patients who as a result of their experience in the palliative care unit are beginning to consider pain relief as a right:

As the doctor says: "Why do you have to bear the pain if there is a way to stop it?" He's right; you shouldn't be in pain if there is something that can stop it. If they do nothing,

it is because they don't want to. (Interview with a female patient, aged 57)

Given their experience in the palliative care unit – an embodied experience – patients jointly give shape to this right to pain relief, which appears as a vehicle for the acknowledgement of rights in medical care. A patient's experience shows the change in expectations produced in some cases – especially in those who had previously had bad experiences – and the critical way of assessing the previously received care in the light of new realities:

It's like this: in just two hours [after arriving at the palliative care unit] I was walking up straight. I couldn't believe it. Well, almost straight; after two days, I was totally straight. It was amazing. I was happy, because for the first time in my life, the pain I had constantly suffered had stopped [...] I have never left here [the palliative care center] without at least knowing what I should do. I either leave without pain, or at least knowing what I should do to ease the pain. When I would visit the oncologist in pain, if the doctor were in a good mood he might prescribe me something to stop the pain; if not, he would make a face, some kind of gesture, and you would have to continue with the pain. (Interview with a female patient, aged 48)

The materialization of the right proposed by the professionals and assimilated by the patients depends on the accessibility and affordability of opioids, a central element present in the initiatives related to this issue (3,5,9). Previous surveys indicate that in Argentina there is good availability of opioids, but limited accessibility to them due to their high cost (8). In the analyzed case, patients under treatment received opioids – preparations containing morphine, methadone or oxycodone – at no charge in the hospital pharmacy, thus guaranteeing this right:

Interviewer: Do you have any difficulty in obtaining the medication?

Patient: I get the morphine and opioid I'm taking now through the hospital for free. That's a great help to me, because if I had

to buy them it would be very expensive. (Interview with a male patient, aged 37)

Although this free supply was available throughout the years that the field work was carried out (from 2006 to 2009), discontinuity in the availability of some of these drugs was documented, compelling professionals and patients to make adjustments: for example, the methadone shortage for some weeks led professionals to change the patients' medication – known as opioid rotation – and in some cases, outpatients had to pay for the medication themselves. As a result of the situations mentioned regarding problems in the affordability of opioids in the country, it is essential to keep a sustained free supply of these drugs in order to ensure compliance with this right.

The rhetoric about the right to pain relief or the possibility of reducing it to tolerable levels is not effectively applied in all cases. Some research studies establish that between 80% and 90% of patients suffering cancer pain could find relief using the WHO recommendations (6). This situation generates expectations that, when not fulfilled, increase the patients' anxiety and suffering. Despite advances in the therapeutic field, in some cases, the patients' pain cannot be controlled (or reduced to tolerable levels). Therefore, assessments of the success or failure of the treatment must be renegotiated or at least analyzed.

Considering pain as a multidimensional phenomenon – that is to say, as a phenomenon that includes psychological and emotional as well as physiological aspects – broadens the universe of meanings, etiologies and implications, but is still problematic in its practical derivations, as has been shown in previous research studies (13,14,19). Professional interventions in cases in which an emotional etiology is suspected are less effective, because there are neither standardized nor proven effective answers. Therefore, establishing the existence of “an emotional component” in the pain that patients express, while useful in clarifying what can be expected in the management of pain and evaluation of the effectiveness of analgesic medication, does not solve the problem.

This situation shows the difficulty in defining *a priori* and externally the thresholds of unbearable and bearable pain and, in a broader sense, it also warns of the limits of medicine in

dealing with the experience of suffering. Physical pain and suffering are complex phenomena that imply the interaction of cultural, social, physiological and biographical aspects (16). An open communication regarding the limitations of the therapeutic efforts and about kinds of pain difficult to treat helps to readjust the expectations of patients, who should be informed about the expected outcome of the treatments.

CONCLUSIONS

This article analyzes palliative care professionals' strategies to implement and establish agreements with patients regarding the terms of the protocol of cancer pain management, as well as the interventions to improve treatment adherence. The association of morphine with terminal disease, the fear of dependence, the side effects of the medication, and the contradictions between preventive treatment and pain management in daily life are barriers to treatment implementation and adherence, upon which professionals actively work. The treatment is part of the proposal to consider pain relief as a matter of rights, a rhetoric which professionals – jointly with the patients – create and reaffirm in daily practice.

Despite medical breakthroughs in this field, pain management is still a problematic issue in health care services, which should ensure the right of this type of patients to access proper and qualified care as well as adequate medication. This article deals with a topic seldom discussed in Argentina, and contributes to raising questions relevant to public health care research and intervention, for instance, cancer pain management, professional knowledge about opioid use, and the availability and accessibility of this type of drugs.

ENDNOTES

a. In 2006, the average consumption of morphine and methadone in Argentine was 0.66 mg and 0.24 mg per capita, while the global average was 8.74 mg and 5.98 mg (8).

b. To protect the anonymity of the people involved the name of the institution is not mentioned.

c. Interviews were carried out as part of an Universidad de Buenos Aires Science and Technology (UBACyT) project directed by Mario Pecheny analyzing concepts and practices related to autonomy in the health field in different groups

of patients, as well as a research study done by Hernán Manzelli about the idea of satisfaction in palliative care as part of a fellowship from the National Ministry of Health.

d. Stake (29) differentiates between intrinsic case studies, in which the selection of the case is guided by an interest in understanding the particular case, and instrumental case studies, in which the case is examined in order to more deeply explore a topic or refine a theory. This research study is of the latter type: the unit has an interdisciplinary team specialized in this type of approach, and includes patients who are at different stages of the disease.

ACKNOWLEDGMENTS

The research was financed with a doctoral fellowship of the National Scientific and Technical Research Council [*Consejo Nacional de Investigaciones Científicas y Técnicas*] (2006-2011) and with an initiatory fellowship in health research from the Health Research Committee [*Comisión Salud Investiga*] of the National Ministry of Health (2008-2009). Without the kind disposition and good will of the staff of the palliative care unit, and especially of patients and their relatives, this research would not have been possible. I appreciate the comments and suggestions of the anonymous reviewers who helped me to improve this article.

BIBLIOGRAPHIC REFERENCES

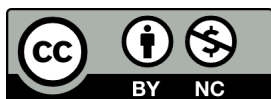
1. Baszanger I. Douleur et médecine, la fin d'un oubli. Paris: Éditions du Seuil; 1995.
2. Swederlow M, Stjernsward J. Cancer pain relief: an urgent problem. World Health Forum. 1982;3(3):325-330.
3. Cohen J, Ezer T, McAdams P, Miloff M, editores. Los cuidados paliativos y los Derechos Humanos: Una guía de recursos. México: Open Society Institute, Equitas; 2007.
4. Brennan F. Palliative care as an international Human Right. Journal of Pain and Symptom Management. 2007;33(5):494-499.
5. Brennan F, Carr D, Cousins M. Pain management: a fundamental Human Right. Anesthesia & Analgesia. 2007;105(1):205-221.
6. O'Mahony S. Cancer pain: prevalence and undertreatment. In: Bruera E, Portenoy R, editores. Cancer pain: assesment and management. Cambridge: Cambridge University Press; 2003. p. 38-47.
7. Hearn J, Higginson IJ. Cancer pain epidemiology: a systematic review. In: Bruera E, Portenoy R, editors. Cancer pain: assesment and management. Cambridge: Cambridge University Press; 2003. p. 19-37.
8. Wenk R. Cancer pain-progress and ongoing issues in Argentina. Pain Research & Management. 2009;14(5):350-351.

9. World Health Organization. National cancer control programmes: policies and managerial guidelines. Ginebra: WHO; 2002.
10. Seymour J, Clark D, Winslow M. Pain and palliative care: the emergence of new specialities. *Journal of Pain and Symptom Management*. 2005;29(1):2-13.
11. Zborowski M. Cultural component in response to pain. *Journal of Social Issues*. 1952;8(4):16-31.
12. Baszanger I. Pain: Its experience and treatments. *Social Science & Medicine*. 1989;23(3):425-434.
13. Csordas T, Clark J. Ends of the line: Diversity among chronic pain centers. *Social Science & Medicine*. 1992;34(4):383-393.
14. Jackson J. "After a while no one believes you": real and unreal pain. In: Delvecchio-Good MJ, Brodwin PE, Good BJ, Kleinman A, editors. *Pain as human experience: An anthropological perspective*. Los Angeles: University of California Press; 1994. p. 138-168.
15. Bendellow G, Williams S. The end of the road?: Lay views on a pain-relief clinic. *Social Science & Medicine*. 1996;43(7):1127-1136.
16. Good B. *Medicine, rationality, and experience: An anthropological perspective*. Cambridge: Cambridge University Press; 1994.
17. Delvecchio-Good MJ, Brodwin PE, Good BJ, Kleinman A, editors. *Pain as human experience: An anthropological perspective*. Los Angeles: University of California Press; 1994.
18. Aldrich S, Eccleston C. Making sense of everyday pain. *Social Science & Medicine*. 2000;50(11):1631-1641.
19. Del Mónaco R. Dolor crónico, corporalidad y clausura: percepciones y experiencias sobre la migración. *Revista Latinoamericana de Estudios sobre Cuerpos, Emociones y Sociedad*. 2012;4(8):17-28.
20. Winslow M, Clark D, Seymour J, Noble B, ten Have H, Meldrum M, Paz S. Changing technologies of cancer pain relief: themes from the twentieth century. *Progress in Palliative Care*. 2003;11(5):256-260.
21. Clark D. "Total pain", disciplinary power and the body in the work of Cicely Saunders, 1958-1967. *Social Science & Medicine*. 1999;49(6):727-736.
22. Kleinman A. *The illness narratives: Suffering, healing and the human condition*. New York: Basic Books; 1988.
23. Le Breton D. *Antropología del dolor*. Barcelona: Seix Barral; 1999.
24. Noble B, Clark D, Meldrum M, ten Have H, Seymour J, Winslow M, Paz S. The measurement of pain, 1945-2000. *Journal of Pain and Symptom Management*. 2005;29(1):14-21.
25. Meldrum M. The ladder and the clock: cancer pain and public policy at the end of the twentieth century. *Journal of Pain and Symptom Management*. 2005;29(1):41-54.
26. Pope C, Mays N, editors. *Qualitative research in health care*. Oxford: Blackwell; 2006.
27. Guber R. *La etnografía: Método, campo y flexibilidad*. Buenos Aires: Norma; 2001.
28. Strauss A, Corbin J. *Basics of qualitative research: techniques for procedures for developing grounded theory*. London: Sage; 1998.
29. Stake R. Case Studies. En: Denzin N, Lincoln Y, editors. *Handbook of Qualitative Research*. California: Sage; 1994.
30. Manzelli H, Bertolino M, Gutiérrez Taddío M, Pecheny M, Farías G, Cullen C. *Satisfacción en cuidados paliativos: un abordaje cualitativo*. Buenos Aires: CEDES; 2004.
31. Scarry E. *The body in pain: the making and unmaking of the world*. New York: Oxford University Press; 1985.
32. Anderson K, Cleeland C. The assessment of cancer pain. In: Bruera E, Portenoy R, editors. *Cancer pain: assesment and management*. Cambridge: Cambridge University Press; 2003.
33. Comité de Derechos Económicos, Sociales y Culturales. Observación general N° 14: El derecho al disfrute del más alto nivel posible de salud (Artículo 12 del Pacto Internacional de Derechos Económicos, Sociales y Culturales) [Internet]. Ginebra: Naciones Unidas; 2000 [cited 10 May 2012]. Available from: <http://goo.gl/NBAVqn>.

CITATION

Alonso JP. Treatment for cancer pain at the end of life: a case study in a palliative care service in the Autonomous City of Buenos Aires. *Salud Colectiva*. 2013;9(1):41-52.

Received: 30 May 2012 | Revised: 5 October 2012 | Accepted: 20 December 2012



Content is licensed under a Creative Commons

Attribution — You must attribute the work in the manner specified by the author or licensor (but not in any way that suggests that they endorse you or your use of the work).

Noncommercial — You may not use this work for commercial purposes.

The translation of this article is part of an interdepartmental collaboration between the Undergraduate Program in Sworn Translation Studies (English < > Spanish) and the Institute of Collective Health at the Universidad Nacional de Lanús. This article was translated by Silvina de Vedia and Mayra Maldonado Avalos, reviewed by María Victoria Illas and modified for publication by Vanessa Di Cecco.